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[Washington]

1943

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STATE PROGRAMS FOR CARE OF CHILDREN WITH RHEUMATIC FEVER

Under the Social Security Act

Title V, Part 2

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U. S. Department of Labor
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CONTENTS

	Page
1. How have State programs for children with rheumatic fever developed?	1
2. How does the typical State rheumatic-fever program work?	2
(a) How is the program administered?	2
(b) What children are eligible for care?	3
(c) How are children in need of care located?	3
(d) What basic professional services are rendered to these children?	3
(1) Medical services	3
(2) Medical-social services	3
(3) Public-health-nursing services	3
(e) How are diagnostic services made available?	4
(f) What treatment services are available?	4
(1) Clinic services	4
(2) Hospital care	4
(3) Convalescent-home care	4
(4) Foster-home care	5
(5) Care in the child's own home	5
(g) How are children transported to the treatment center?	5
(h) How are the child's educational needs met during his illness?	5
(i) What vocational guidance is given?	5

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STATE PROGRAMS FOR CARE OF CHILDREN WITH RHEUMATIC FEVER UNDER THE SOCIAL SECURITY ACT, TITLE V, PART 2

1. *How have State programs for children with rheumatic fever developed?*

The Social Security Act, passed in 1935, authorized the appropriation of Federal funds for services for crippled children. These funds are paid to the States after annual State plans for such services have been approved by the Chief of the Children's Bureau of the United States Department of Labor.

No definition of "a crippled child" has ever been made by the Children's Bureau. During the first 5 years of administering services for crippled children under the Social Security Act the States gave major attention and care to children with orthopedic or plastic conditions, but there was a growing interest among both lay and professional groups in making services available to children with other crippling conditions. The recommendation of the American Academy of Pediatrics at its regional meeting in Rochester, N. Y., November 1938, that heart disease should be considered a crippling condition, gave special impetus to the idea that children with rheumatic fever and heart disease should be eligible for services under crippled children's programs. Consequently, in 1939, when the need for additional Federal funds for crippled children's services was brought to the attention of Congress, the special need of children with rheumatic fever for such funds was pointed out. The additional funds authorized at that time were provided with the understanding that a portion of the funds would be used for assisting State agencies in developing services for such children.

As a first step in the development of programs of care for children with rheumatic fever, the Chief of the Children's Bureau called together a small committee of pediatricians and other recognized authorities in this field. General policies for the development and administration of a program of services for children with rheumatic fever were outlined by this group, and these policies have served as a guide in the planning of State rheumatic-fever programs.[1]

Several State plans for rheumatic-fever programs were developed in the spring of 1940, and others have been developed since that time. At present 14 States have programs in operation for the care of children with rheumatic fever or heart disease (California, Connecticut, District of Columbia, Idaho, Iowa, Maine, Maryland, Minnesota, New York, Oklahoma, Rhode Island, Utah, Virginia, and Washington). About 5 other States intend to submit plans for rheumatic-fever programs during the fiscal year 1943; and at least 10 additional States have informed the Children's Bureau of their serious interest in such a program. It will be impossible for every State in the Union to receive additional Federal funds for the provision of services to children with rheumatic fever until further funds are made available through amendment of the Social Security Act.

[1] Copies of these recommendations are available at the Children's Bureau, U. S. Department of Labor, Washington, D. C.

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2. *How does the typical State rheumatic-fever program work?*

The typical State rheumatic-fever program serves a small area of the State, usually one to four counties; it is set up in a locality where it is possible to organize a complete program of care for children with rheumatic fever or heart disease, including good medical, medical-social, and public-health-nursing services, and facilities for adequate diagnostic, hospital, "sanatorial," and convalescent care, and aftercare.

Continuity of care for these children has been considered of the utmost importance in the planning of State cardiac programs. Children with rheumatic fever or heart disease, once they are accepted for care by the State agency, are kept under continuing care for long periods of time, not only because rheumatic fever—the most important cause of heart disease in childhood—is a chronic disease requiring long periods of treatment in hospital, convalescent home, foster home, and so on, but also because the danger of recurrence is ever present. In the typical State rheumatic-fever program, in accordance with general medical principles, children under care are examined periodically in order that early signs of recurrence may be detected and treatment instituted; and, in addition to the treatment of conditions specifically related to rheumatic fever or heart disease, any treatment necessary to improve the general condition of the child is arranged for, either directly through the expenditure of crippled children's funds (State and Federal) or indirectly by the use of other community resources.

It was believed that if a small number of children in a limited area of a State were taken care of completely and adequately and their problems studied, it would be easier later to extend services to other areas of the State. Already the State agencies that have begun rheumatic-fever programs have received many requests for the extension of services to new areas, and in some States the program has been expanded to include two or three additional counties; but expansion of any considerable extent must await the granting of additional funds under the Social Security Act or funds from State or local sources.

(a) *How is the program administered?*

The official State agency which administers services for crippled children also is responsible for the administration of the rheumatic-fever program. This agency is, in the majority of States, the department of health; in others it is the department of public welfare, the department of education, a special State commission, or the State university hospital. In a few State departments of health the rheumatic-fever program is placed in the maternal and child-health division rather than in the crippled children's division.

Medical leadership in planning and developing services for children with rheumatic fever or heart disease is provided by the State agency through the employment of a physician with special knowledge of this field; almost without exception the State agencies have chosen pediatricians to fulfill this function.

The State agency also appoints an advisory committee, composed of representatives of the various professional fields involved in a program of this type—medical, social, nursing, education, and so forth.

Consultation on administrative, medical, medical-social, and public-health-nursing problems is made available to the State agency by the Children's Bureau.

(b) *What children are eligible for care?*

Children under the age of 21 with heart disease or conditions leading to heart disease are eligible for care. In all the State programs emphasis is given to the care of children with rheumatic fever or rheumatic heart disease, particularly early in the disease, but children with other types of heart disease which offer a reasonable expectation of improvement through treatment are also eligible for care. In general, diagnostic services are available to all children living in the area served, but a child is accepted for further care only when it has been determined that the child's family is unable to meet, in part or in whole, the expenses of prescribed treatment.

(c) *How are children in need of care located?*

The most important source for locating children in need of diagnosis or care has been referrals by physicians who have discovered such children in their private practice and in schools, hospitals, clinics, and so forth. Other sources for locating these children have been referrals by public-health nurses, health departments (especially in places where rheumatic fever is a reportable disease), school nurses and teachers, child-health conferences, crippled children's clinics, social-welfare agencies, and parents. Since rheumatic fever has a high familial incidence, a number of State rheumatic-fever programs place special emphasis on the examination of other children in the family of a rheumatic child.

(d) *What basic professional services are rendered to these children?*

(1) *Medical services.*—A pediatrician employed by the State agency on a part-time or a full-time basis is directly responsible for medical care of these children in all stages of treatment, whether in clinic, hospital, convalescent home, foster home, or the child's own home. In this way continuity of medical care is assured. The pediatrician in every case is certified by the American Board of Pediatrics or is eligible for such certification. When possible, the State agency has selected a pediatrician who has had special training and experience in the field of rheumatic fever and heart disease in children. In some States where it was impossible to find such a person, well-qualified pediatricians were appointed and subsequently were given special training. Consultation services by cardiologists, surgeons, and specialists in other branches of medicine and surgery are provided when necessary by qualified consultants who are certified by, or eligible for certification by, the boards of their respective specialties. Fees for such services are paid by the State agency.

(2) *Medical-social services.*—A medical-social consultant employed by the State agency is responsible for meeting the medical-social needs of these children. In the beginning of the program this type of worker has been giving a good deal of direct service to these children in connection with all phases of their care but as the program continues her function is becoming more and more that of a consultant, developing and helping to improve the social services available in the community to these children.

(3) *Public-health-nursing services.*—A public-health-nursing consultant on the staff of the State agency supervises the public-health-nursing services for children under this program. The programs are conducted in places where

generalized public-health-nursing services are available. The consultant on the State staff is responsible for teaching and otherwise assisting the local public-health nurses to provide good nursing care for the child with rheumatic fever or heart disease.

(e) *How are diagnostic services made available?*

For the most part diagnostic services are provided by the pediatrician in clinics where all the necessary laboratory facilities for diagnosis are present, including fluoroscopic and electrocardiographic machines. If, for diagnosis, observation or any procedure too elaborate for the clinic is necessary, children are hospitalized for diagnosis. When diagnostic services are needed for a child who is too sick to come to the clinic, the pediatrician makes a home visit. Consultative diagnostic services are available to private physicians.

(f) *What treatment services are available?*

(1) *Clinic services.*—Regular clinics are held under the State rheumatic-fever program to provide diagnostic services and follow-up care. These clinics are conducted by the pediatrician. A medical-social worker and a public-health nurse are present in order that social and nursing services may be provided as well as medical services. Only six to eight children are given appointments for a half-day clinic session, and it has thus been possible for each child to have a thorough work-up, including medical history, physical examination, social history, and laboratory tests.

(2) *Hospital care.*—During acute illness children receive care in a hospital which has a special pediatric ward with a pediatric staff, medical and nursing, and which meets the other standards set up by the Children's Bureau advisory committee. The pediatrician employed by the State agency either takes care of the child during his hospital stay or acts as a consultant during this period.

Children are kept in the hospital only during the acute stage of the disease and then are transferred elsewhere for a period of prolonged bed rest during the chronic stage. This type of care, which may be termed "sanatorial" care, is usually provided in a convalescent home, a foster home, or the child's own home, as sanatoria for this purpose are not generally available. In four States, however, children are transferred from the general pediatric ward to a special ward in the same hospital for "sanatorial" care.

(3) *Convalescent-home care.*—In about half the State programs children are given "sanatorial" care, during the chronic phase of rheumatic fever, at convalescent homes where medical, nursing, and social supervision are adequate for the care of the sick child in bed. Convalescent homes are also being used for children who have entirely recovered from rheumatic fever but who are not physically up to par because of the recent attack of rheumatic fever or some other illness.

The convalescent homes which are being used in State rheumatic-fever programs meet the standards set up by the Children's Bureau advisory committee in regard to medical, nursing, social, and nutritional supervision, isolation facilities, adequate records, and provision for recreation.

(4) *Foster-home care.*—In some States, where no suitable convalescent homes are available and where a special ward in the hospital cannot be set aside, foster homes are the only resource available for providing long-time bed care for children in the chronic stage of rheumatic fever, if the child's own home cannot be made adequate for this purpose. In other States, which have facilities for "sanatorial" care in hospitals or convalescent homes, care in a foster home seems preferable to institutional care for some individual children.

Plans for care in foster homes are developed in cooperation with child-welfare agencies. Standards for foster homes to be used for sick children under this program include medical, nursing, social, and nutritional supervision, and provision for recreation and education.

(5) *Care in the child's own home.*—Services in the child's own home include diagnostic services for the child who is physically unable to attend a clinic and treatment for the child with rheumatic fever or other illness if he can be well cared for in his own home. Important in the aftercare of the child are adjustments in the home situation to meet any personal and environmental difficulties which obstruct the treatment and care of the child. Efforts to meet these difficulties are made, either by the personnel of the State agency or by other local or State agencies, after joint planning by the pediatrician, the medical-social consultant, and the public-health-nursing consultant.

(g) *How are children transported to the treatment center?*

If means of transportation are not available to the child through his own family, transportation is usually arranged in cooperation with local community agencies. Ambulance service is provided by the State agency when necessary.

(h) *How are the child's educational needs met during his illness?*

Although education of the physically handicapped child does not fall within the scope of services which may be provided by the use of social-security funds, State agencies have recognized that the education of these children must be provided for in some way.

Provisions for the child's education while he is on prolonged bed rest are usually made by the State board of education. In many States provisions are made for bedside teaching in hospitals and convalescent homes, and in some States visiting teachers provide education for the child in his own home or in a foster home. In the few States in which the State board of education makes no provision for teaching outside of the classroom, efforts are being made to promote this type of service.

(i) *What vocational guidance is given?*

In most of the State programs arrangements are made through State vocational-rehabilitation services for the vocational guidance of adolescent children with serious cardiac damage.

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